



FOCUS Alternative Learning Center, Inc.

Specializing in the treatment of children and adolescents who are on the Autism Spectrum, have anxiety disorders, experience processing and social learning difficulties; and who are otherwise, as we like to say, "creatively wired and socially challenged."

Good morning. Thank you for the opportunity to speak today. I am here to support House Bill #5666. AN ACT CONCERNING EXPANSION OF THE PILOT PROGRAM FOR PERSONS WITH AUTISM SPECTRUM DISORDERS. My name is Jessica Rhodes. I am here as a Clinician for FOCUS Alternative Learning Center in Canton, CT. I am also a parent to a wonderful 6 year old boy with Autism, and we reside in Simsbury.

FOCUS provides a therapeutic extended day treatment program, not typical of extended day treatment programs, to people we consider "creatively wired and socially challenged." This is what neuro-typical people call an Autism Spectrum Disorders (ASD), a term sometimes interchangeable with Pervasive Developmental Disorder (PDD). The umbrella term of PDD/ASD affects each person differently in several areas, including Socially, Behaviorally, as well as how they communicate and perceive the world through their senses. This large spread of challenges includes: Aspergers, Autism, PDD-Not Otherwise Specified, Rett's, and CDD (Childhood Disintegrative Disorder); which is why it is called a spectrum disorder. With all of these disorders, there are usually co-morbid diagnoses, which include: Sensory Integration Disorder, ADHD, Anxiety, Depression, and OCD to name a few.

During the Autism diagnostic process, many tests are given to rule out (or rule in) aptitudes. One of these tests is an Intelligence Scale—one of the ways that Mental Retardation is determined. Even though there are various clinical needs of people with Autism, MR isn't necessarily one of them. If the client with Autism does not have Mental Retardation as a co-diagnosis, then services from the (formally named) Department of Mental Retardation, now called Department of Developmental Services, stop when a child turns 7—unless severe cognitive and adaptive delays are proven. Someone with ASD could be severely affected by the social, behavioral, and sensory components of Autism—but, currently, if they are not cognitively or adaptively affected, their services are limited and discontinued. One in 150 people have Autism. It will cost the government millions, actually billions, to deal with this population if they are underserved. Wouldn't it be better to teach these people how to work and live in our society so they can contribute? If we teach them, and they are teachable, they will be able to function as members of our society—which is their human right!

When I was here to testify last week on house Bill #5696 (An Act Requiring Insurance Coverage for Autism Spectrum Disorders), many questions from Representatives were, "what about the children not included on this bill?" It seemed that there was misunderstanding—HB#5696, along with HB#5666 are bills of INCLUSION—finally this population with PDD/ASD, is being included where they have previously been excluded. During that testimony, I was also surprised by the number of representatives who asked why schools weren't taking more of the burden. That is a great question! Public Schools are not equipped to care for the non-academic needs of children with ASD, 7 days a week. Our children are only in school for 180 days of the year—until the child "graduates" or reaches the age of 21, whichever comes first. Schools do not cater to medical needs nor do they focus enough attention on adaptive life skills.

"Learning to embrace our differences"

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Because these people have ASD/PDD, they are facing additional discriminations that other people with special needs are not. The "A" in Autism is truly the Scarlet Letter of this generation. We are failing this population by allowing this discrimination to continue. We are currently working on getting insurance companies to stop denying our claims for medical services—and that is a fight. We are working on schools to provide more services for our children—that, too, is a fight. There is a lack of trained professionals to work with our children. We are asking higher Educational Institutions in Connecticut to create programs that teach educators about people with Autism—but that is a fight. Frankly, all of these places are just another place our children get misunderstood and turned away.

We asked that DMR help create programs that help our children. AND THEY HAVE. They became DDS and created this pilot program. Now we ask that you allow them to expand the pilot program so that our children aren't cut off from services. We need this expansion so that we can continue to provide them with programs for job development, life skill development, social skill coaching, and independent living skills. We need this pilot program and more like it—who understand these children and their families. This pilot program is doing a wonderful service, however, it is only doing a SMALL service—right now they only service less than 50 people. Please give DDS the opportunity to expand this program!

As a parent, I am kept awake at night wondering what will happen to my child when he "graduates" from High School. I am sure that this is a fear that all parents share, however, most parents don't have to worry who is going to care for their child when he or she reaches adulthood—because their adult child will be able to fend for him or herself. My son, without extra assistance and hard work, will not be able to fend for himself. He did not do anything to deserve this challenge—he was just born. And this society is constantly expecting him to do (or "get") better, but not providing him with the resources to do that. DDS is trying to provide us with those resources—will you let them?

Respectfully,



Jessica Rhodes, M.A.

Clinician, School Counselor

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